DOCUMENT RESUME

ED 330 134 EC 300 104

AUTHOR	Horne, Richard, Ed.
TITLE	Accessing Programs for Infants, Toddlers, and Preschoolers with Disabilities.
INSTITUTION	Interstate Research Associates, Inc., Washington, D.C.; National Information Center for Handicapped Children and Youth, Washington, DC.
SPONS AGENCY	Special Education Programs (ED/OSERS), Washington, DC.
PUB DATE	Sep 90
CONTRACT	G0087C3051
NOTE	21p.
PUB TYPE	Guides - Non-Classroom Use (055) -- Reference Materials - Vocabularies/Classifications/Dictionaries (134) -- Collected Works - Serials (022)
JOURNAL CIT	A Parent's Guide; Update Sep 1990
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	Adopted Children; At Risk Persons; Delivery Systems; *Disabilities; *Early Intervention; Federal Legislation; Foster Children; Infants; Military Personnel; Preschool Children; Preschool Education; Recordkeeping; Services; *Special Education; Student Evaluation; Toddlers
IDENTIFIERS	Education for All Handicapped Children Act; Education of the Handicapped Act Amendments 1986; *Individualized Family Service Plans

ABSTRACT

Intended for use by parents of infants, toddlers and preschoolers, this guide presents, in question and answer format, basic information about early intervention and special education services. Questions about services for the period from birth through 2 years include the following: "What are early intervention services?" "What is an assessment?" and "What is an Individualized Family Service Plan?" Questions about special education programs for children ages 3 through 5 include: "What should I do if I think my preschool child needs special education?"; "Whom do I contact first for help?" and "Will I have to pay for the assessment or for services my child is eligible for?" Next are questions and answers specifically about programs and services for rural, American Indian, adoptive/foster, and military families. A parent's dictionary provides definitions of 40 terms commonly encountered in special education. Brief summaries are also provided of the major provisions of Public Law 94-142, the Education for All Handicapped Children Act and Public Law 99-457, the Education of the Handicapped Act Amendments of 1986. An annotated bibliography of 12 references is also included, as is a sample record-keeping worksheet. (DB)

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A PARENT'S GUIDE

Accessing Programs For Infants, Toddlers, and Preschoolers With Disabilities

Update September, 1990

Thank you for contacting the National Information Center for Children and Youth with Handicaps (NICHCY). We have written this information to help families of young children with **special needs** (ages birth through 5 years) learn how to get help for their children.

We have posed the most asked questions to NICHCY about **early intervention services** for children ages birth through 2 years old and **special education services** for children ages 3 through 5 years old and have tried to answer them.

The rules or guidelines for **special education** in the United States and its territories are outlined in a federal law known as **Public Law(P.L.)94-142**. Each state or territory develops its own **policies** for carrying out **P.L.94-142,** The Education for All Handicapped Children Act, and its amendments, P.L.98-199 and P.L.99-457. (You can read more about this law beginning on page 16.)

You'll need to find out what the **early intervention** or **special education policies** are in your state and area. The list of agencies and contact people in your state should help you get started. A NICHCY *State Resource Sheet* for your state is attached.

The phrases "children with **special needs**" or "**special needs** children" are used throughout this document to refer to children who have **disabilities** or who are at risk for developing **disabilities**.

Words in **bold** are defined in the Parent's Dictionary that begins on page 12.

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EC 300104

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PART I:

Questions and Answers About Early Intervention Services For Infants and Toddlers Who Have a Disability or Are At Risk for Developing a Disability (Ages Birth Through 2 Years Old)

Note: Words that appear in **bold** are words that are commonly used in **special education**. Many may be new to you. We have used these terms to help you become familiar with them. You can look up their definitions in the Parents' Dictionary that begins on page 12.

We have used the term "parents" to mean anyone who is in charge of the care and well-being of a child. These can be guardians, single parents, grandparents, surrogate parents, or foster parents.

A new federal law known as **Public Law(P.L.)99-457** guarantees certain rights to young children (ages birth to 5) with **special needs**. This law is the most recent **amendment** to **Public Law(P.L.)94-142**. (To learn more about both of these laws, see pages 16 and 17.)

Q: What should I do if I think my child has special needs?

A: First, you'll need to find out if your infant or toddler is **eligible** for **early intervention services**. There are many people who can help you with this. We will explain how to get the help you need in the pages that follow.

Q: What are early intervention services?

A: These are **services** for infants and toddlers that are designed to identify and treat a problem or delay as early as possible. **Early intervention services** are offered through a **public agency** and are provided in different settings, such as the child's home, a clinic, a neighborhood center, or the local health department.

Early intervention services can range from prescribing glasses for a two-year-old to developing a complete **physical therapy** program for an infant with cerebral palsy.

Q: Whom do I contact first for help?

A: Each state decides which of **its agencies** will be the **lead agency** in charge of **early intervention services** for infants and **toddlers** with **special needs**. In your state, the first contact person may be an **early childhood specialist, someone** with the **lead agency**, or someone in your state's **Child Find** office.

To find out **who can help you, call your** local **elementary** school or local school district office and ask **for the person in your area who is in charge** of **programs** for infants and toddlers with **special needs.**

Or, contact the person listed under "Programs for Infants and Toddlers with Handicaps" listed on your *State Resource Sheet*. Explain to whomever you talk to that you want to find out about **early intervention services** for your child.

Important. Write down the names and phone numbers of everyone you talk to. (You can use the Sample Record-Keeping Worksheet at the bottom of page 20 as a guide.) Having this information available may be helpful to you later on.

Q: *What do I say when I talk to my local contact person?*

A: Explain that you think your child may need **early intervention services** and you would like to arrange for an **assessment**. Write down any information you are given.

Q: *What is an assessment?*

A: An **assessment** is the process of gathering and using information about how a child is developing and determining what kind of help he or she might need. It is a way of observing and **evaluating** a child to see if he or she is **eligible** for **early intervention services**.

This information may come from some, or all of the following:

- Doctor(s') reports;
- Results from **developmental tests** given to your child;
- Your child's medical history;
- Observations and feedback from all members of the **assessment team**, including parents; and
- Any other important observations, records, and/or reports about your child.

Q: ***Who does the assessment?***

A: It depends on your state's **policies** or rules. Ask your local contact person about this. Usually, a team of professionals which may include a **psychologist**, an **early childhood specialist**, and an **occupational** or **physical therapist** will test a child.

Q: ***Who pays for the assessment?***

A: Under **P.L.99-457**, **assessments are provided** at no cost to families. Check with your contact person for local guidelines.

Q: ***Will I have to pay for any services my child is found eligible for?***

A: You may or may not have to pay for some services, depending on your state's **policies**. Check with the contact person in your area or state. Some **services** may be covered by your health insurance, by Medicaid, or Indian Health Services.

Generally, they are provided at no charge. In some areas, however, you may be charged a "sliding-scale" fee that is based on what you earn. Every effort is made to provide **services** to all infants and toddlers who need help, regardless of family income.

Q: What's a case manager?

A: This person should have a background in early childhood development and know the policies for **early intervention programs** and **services** in your state. This person can help you locate other **services** in your community, like recreation, child care or family support groups. The **case manager** will work with your family as long as your baby is receiving **early intervention services** and, when your child is 2 years old, the **case manager** will help your family move on to **programs** for children ages 3 through 5.

Q: What's an IFSP?

A: When a child's needs are assessed and the child is found **eligible** for **services**, a **case manager** will be assigned to the family and together they will develop an **Individualized Family Service Plan**, or **IFSP**. The guiding principal of the IFSP is that the family is a child's greatest resource; that a baby's needs are closely tied to the needs of their family. The best way to support children and meet their needs is to support and build upon the individual strengths of their family. So the **IFSP** is a whole family plan with the parents as the most important part of that team. Other team members will depend on what the baby needs. These other team members could come from several agencies, and may include medical people, therapists, child development specialists, social workers and others. The **IFSP** will describe the services the child will be receiving, when and where he'll receive these services, and how his progress will be evaluated. The **IFSP** can also include services the family may be interested in, such as financial information or information about raising a child with a disability.

Each state has developed specific guidelines for the **IFSP**. Your **case manager** can explain what **IFSP** guidelines are in your state.

Q: Are there any parent groups in my area that can give me more information about early intervention services?

A: There are several types of parent groups, including:

- Support groups (such **as Parent**-to-Parent) for families of children with **disabilities**;
- **Parent training and information programs** funded by the federal government, such as **the Technical Assistance** for Parent Programs [TAPP] Project; and
- Groups **concerned with a specific disability**, such as United Cerebral **Palsy** Associations, Inc. **(UCPA) or the** Association for Retarded Citizens **of the United States (ARC).**

We have listed some of these groups on your attached *State Resource Sheet*.

Parent groups can offer information, support, and/or training to families of children with **disabilities** to help parents take a more active role in helping their children. Through such groups, families meet other families with similar needs to discuss resources, day-to-day problems, and personal insights.

Someone at your local school or at your state or regional parent center may be able to tell you about nearby groups. For more details on parent groups, contact NICHCY and ask for our "Parent's Guide to Accessing Parent Programs." (1-800-999-5599)

Q: ***I still have a lot of questions. How can I find out more about special education laws and about early intervention services?***

A: See pages 16 and 17 for more information on two important **special education** laws. Also, see the "References" section beginning on page 18 for selected additional information on the development of infants and toddlers with **disabilities**, on **early intervention programs and services**, and on raising and caring for a young child with **special needs**.

Once your child has been found **eligible** for **early intervention services**, your family will be assigned a **case manager**. As time goes on, you will probably have more questions. For example, you might want to know:

- How do I check on the **services** my child is getting?
- What do I do if I am not satisfied with my child's **assessment, program**, or progress?
- What happens to my child once he/she is too old for the **program**?
- What about **private therapists** and private schools?

For answers to these and other questions, talk to your **case manager** or contact a parent **support and/or training** group in your area.

We hope these materials are useful. If you need more help or information from NICHCY, **please call us (toll free) at 1-800-999-5599** or write to us at this address:

NICHCY
P. O. Box 1492
Washington, D.C. 20013

PART II:

Questions and Answers About Special Education Programs and Services for Preschoolers With Disabilities (Ages 3 Through 5 Years Old)

Note: Words that appear in bold are words that are commonly used in special education. Many may be new to you. We have used these terms to help you become familiar with them. You can look up their definitions in the Parent's Dictionary that begins on page 12.

The phrases "special education," "special education programs," "special education services," and "special education programs and services" are used interchangeably in this section.

Below are answers to questions people often ask about special education programs and services for preschool children ages 3 through 5 years old who have disabilities.

A new federal law known as Public Law(P.L.)99-457 guarantees certain rights to young children (ages birth to 5) with special needs. This law is the most recent amendment to Public Law(P.L.)94-142, The Education of all Handicapped Children's Act.

Q: What should I do if I think my preschool child needs special education?

A: If you think your preschooler needs special education, you will first want to find out if he or she is eligible for a special education program. There are people who can help you with this. Read on and we will explain how to contact them.

Q: What are special education programs?

A: Special education programs are specially designed programs in public schools offered at no cost to families of children with disabilities. In some public schools, children ages 3-5 with disabilities already can receive special education services under P.L.94-142.

Today, under P.L.99-457, most, if not all, schools must offer special education services to eligible 3-5 year olds with disabilities.

Q: Whom do I contact first for help?

A: The best place to start is your local public elementary school. (In most cases, this would be the school in your neighborhood.) Call and ask to speak to the principal or to someone in charge of special education at the school.

Or, look on the attached *State Resource Sheet* under "State Department of Education" for the early childhood or preschool specialist for children (ages 3-5 years) or for the person listed there who would most likely be able to help you, or could refer you to the appropriate per-

son. Explain to whomever you talk, that you want to find out about special education services for your child. Ask what you need to do to arrange for an assessment.

Write down the names and phone numbers of everyone you talk to. (You can use the Sample Record-Keeping Worksheet at the bottom of page 20 as a guide.) Having this information available may be helpful to you later on.

Q: *What is an assessment?*

A: An assessment is the process of gathering and using information about your child's development and the kind of help he or she might need. It is a way of observing and evaluating your child to see if he or she is eligible for special education services.

This information may come from:

- Doctor(s') reports;
- Results from developmental tests given to your child;
- Your child's medical history;
- Observations and feedback from all members of the assessment team, including parents; and
- Any other important observations, records, and/or reports about your child.

Q: *Who does the assessment?*

A: It depends on the rules in your state or school district. Ask your school contact person what the policy is for getting an assessment for your child.

Q: *Will I have to pay for the assessment or for any services my child may be eligible for?*

A: In general, special education services are either already or should be offered for 3-5-year-olds at no cost to parents. The assessment generally is considered part of these services.

Assessments given by a school district are provided at no cost to families.

Q: *Are there any parent groups in my area that can give me more information about special education?*

A: There are several types of parent programs, including:

- Support groups (such as Parent-to-Parent) for families of children with disabilities;
- Parent training and information programs funded by the federal government, such as the Technical Assistance for Parent Programs [TAPP] Project; and
- Groups concerned with a specific disability, such as United Cerebral Palsy Associations, Inc. (UPCA), or the Association for Retarded Citizens of the United States (ARC).

We have listed some of these groups on your *State Resource Sheet*. You can also check with someone in your local school district or at your local school.

Parent groups can offer information, support, and/or training to families of children with disabilities to help them take a more active role in their children's education. Through such groups, families meet other families with similar needs to discuss local resources, daily problems, and personal insights. For more details on these and other parent groups, contact NICHCY and ask for our "Parent's Guide to Accessing Parent Groups."

Q: *I still have a lot of questions. How can I find out more about special education programs and services?*

A: See pages 16 and 17 to learn more about two important special education laws. Also, see the "References" section beginning on page 18 for information on raising and caring for a young child with special needs.

Once your child has been found eligible for special education, you will most likely have more questions. For example:

- How do I check on my child's special education program?
- What do I do if I am not satisfied with my child's assessment, placement, program, or progress?
- What happens to my child when he/she is too old for the program?
- What about private therapists and private schools?

For answers to these and other questions, talk to your special education coordinator or school principal or contact a parent support and/or training group in your area.

Also, write to NICHCY and ask for our "Legal Pack." It contains information about special education laws and parents' rights in getting school services for their children with disabilities.

We hope these materials are useful. If you need more help or information from NICHCY, please call us (toll free) at 1-800-999-5599 or write to us at this address:

NICHCY
P. O. Box 1492
Washington, D.C. 20013

PART III:

Questions and Answers About Programs and Services for Rural, American Indians, Adoptive/Foster, and Military Families and Their Young Children With Disabilities

Q: What about services for families in remote or rural areas?

A: The goals of early intervention or special education programs and services for young children with special needs is the same for both rural and urban families. However, the ways in which these services are offered may be different. One group that may be able to offer information specifically about services for rural families is:

American Council on Rural Special Education (ACRES)
Western Washington University
359 Miller Hall
Bellingham, Washington 98225
(206) 676-3576

ACRES is a national organization of professionals and parents who work together to improve services in rural areas to children with disabilities. ACRES publishes many useful materials, including a State Department of Education "Rural Representatives Directory" which lists the names of people at the state level you can contact.

Q: What about services for American Indian families living on reservations?

A: The lead agency for the state provides early intervention programs and services for all young children with special needs in the state, including American Indian infants, toddlers and children residing on reservations. The Bureau of Indian Affairs (BIA) also makes available early intervention programs for Indian infants and toddlers on certain reservations. Information on these services for Indian children with special needs is available by contacting the state lead agency or BIA Office of Indian Education Programs; the nearest public and/or BIA elementary school; local Head Start centers and programs; Indian Health Service (IHS) offices, clinics or hospitals; as well as BIA and/or tribal social services programs.

Indian families who live in areas served by BIA schools may have a choice between Bureau or state early intervention services. Check with the agencies, schools, and programs serving your reservation for available services and details.

*Q: What information and support groups are **available to help families**?*

A: There are several types of parent groups **including:**

- Support groups (such as Parent-to-Parent) **for families** of children with **disabilities**;
- Parent Training and Information Projects **funded** by the federal government.
- Groups concerned with a specific **disability,** such as United Cerebral Palsy Associations, Inc. (UCPA) or the Association **for** Retarded Citizens of the United States (ARC); and
- Education for Parents of Indian Children with Special Needs (EPICS), a Parent Training and Information Project in New Mexico which provides **services** for Indian parents of children with **special needs**.

Q: What additional information do families of adopted or foster children with disabilities need about early intervention or special education services?

A: In general, the process for getting **early intervention** or **special education programs and services** for legally adopted children with **special needs** is the same as it is for all children with **special needs**.

An organization that has a nationwide family support **network** of adoptive **families** is OURS (Organization for United Response). While the main **focus of** this organization **is to** provide general help and information to all adoptive families, its **bimonthly** parent **support** magazine includes information and resources for families of adopted **children who have special needs**. (You can write to them for an index of OURS magazine articles.)

The address for OURS is:

The Organization for United Response (OURS), Inc.
3333 Highway 100, North, Suite 203
Minneapolis, MN 55422
(612) 535-4829

Families that provide foster homes to children who have **disabilities or who are at risk** of developing **disabilities** may want to contact the National Foster **Parent Association,** Inc. (NFPA). This national, non-profit group offers information and **support to all foster** parents. Members of the group receive a bimonthly newsletter and nine **issues of the *Foster Care** Journal*. They are also able to use all NFPA resources.

For the Information/Services Office of NFPA, contact:

National Foster Parent Association, Inc.
Information/Services Office
226 Kilts Drive
Houston, TX 77024
(713) 467-1850

Q: ***How do I find out about programs and services for military families whose young children have special needs?***

A: One way is through a project known as Specialized Training of Military Parents (STOMP). This organization provides information and help to military families (both in the U.S. and overseas) who have children with **special needs**.

The STOMP staff is made up of parents of children with **special needs** who are trained to work with other parents of children with **special needs**. As spouses of members of the military, the staff understands the unique needs of military families.

To contact STOMP, call or write:

Specialized Training of Military Parents
(STOMP)
700 N. Oak St., Suite A
Valdosta, GA 31601
(912) 244-4735

Or

Specialized Training of Military Parents
(STOMP)
12208 Pacific Highway, SW
Tacoma, WA 98499
(206) 588-1741

(Call either number collect if you are a member of a military family.)

Another way to learn more about early intervention and special education programs and services for children in military families stateside is to contact the Community Service Center (also called Family Service Center or Family Resource Center) or the assigned community contact person on your installation.

While most children of military families attend (or will attend) public schools, some are in Section VI schools. Each Section VI school will follow its own state's plan for planning programs under P.L.99-457. If you need more information, call or write the contact person in your state education agency. (See your *State Resource Sheet*)

The office of Department of Defense Dependent Schools (DODDS) overseas issues a handbook for military families with children who have special needs and are receiving, or are eligible to receive, a free appropriate public education through DODDS overseas. (At present, DODDS overseas has 36 programs for preschool children with disabilities [ages 3-5].) To order the handbook, write to:

Department of Defense Dependent Schools (overseas)
Special Education Coordinators
2461 Eisenhower Avenue
Alexandria, VA 22331-1100

PARENT'S DICTIONARY OF TERMS USED IN SPECIAL EDUCATION*

*Note: The following definitions have been compiled from a variety of sources. The contents of this dictionary do not necessarily represent definitions endorsed by the U.S. Department of Education.

advocate - someone who takes action to help someone else (as in "educational advocate"; also, to take action on someone's behalf

amendment - a change, revision, or addition made to a law

appeal - a written request for a change in a decision; also, to make such a request

appropriate - able to meet a need; suitable or fitting; in special education, it usually means the most normal setting possible

assessment - a collecting and bringing together of information about a child's learning needs, which may include social, psychological, and educational evaluations used to determine assignment to special programs or services; a process using observation, testing, and test analysis to determine an individual's strengths and weaknesses to plan his or her educational services

assessment team - a team of people from different areas of expertise who observe and test a child to determine his or her strengths and weaknesses

at risk - a term used with children who have, or could have, problems with their development that may affect later learning

case manager - someone who acts as a coordinator of an infant's or toddler's services and works in partnership with the family and providers of special programs; case managers are employed by the early intervention agency

Child Find - a service directed by each state's Department of Education for identifying and diagnosing unserved children with handicaps; while Child Find looks for all unserved children, it makes a special effort to identify children from birth to six years old

cognitive - a term that describes the process people use for remembering, reasoning, understanding, and using judgement

counseling - advice or help given by someone qualified to give such advice or help (often psychological counseling)

developmental - having to do with the steps or stages in growth and development before the age of 18

developmental history - the developmental progress of a child (ages birth to 18 years) in such skills as sitting, walking, or talking

developmental tests - standardized tests that measure a child's development as it compares to the development of all other children at that age

disability - the result of any physical or mental condition that affects or prevents one's ability to develop, achieve, and/or function in an educational setting at a normal rate

due process (procedure) - action that protects a person's rights; in special education, this applies to action taken to protect the educational rights of students with handicaps

early childhood specialist - someone who specializes in early childhood development, usually having a Master's degree or Ph.D. in an area related to early childhood education and/or development

early intervention policies - see policy/policies

early intervention services or programs - programs or services designed to identify and treat a developmental problem as early as possible

eligible - able to qualify

evaluating - analyzing a child's special learning needs

evaluation - (applies to school-aged children); a way of collecting information about a student's learning needs, strengths, and interests; the evaluation is part of the process of determining whether a student qualifies for special education programs and services

free, appropriate public education [often referred to as FAPE] - one of the key requirements of Public Law 94-142, which requires that an education program be provided for all school-aged children (regardless of disability) without cost to families; the exact requirements of "appropriate" are not defined, but other references within the law imply the most "normal" setting available

handicap - see disability

identification - the process of locating and identifying children needing special services

Individualized Education Program (IEP) - a written education plan for a school-aged child with disabilities developed by a team of professional (teachers, therapists, etc.) and the child's parents; it is reviewed and updated yearly and describes how the child is presently doing, what the child's learning needs are, and what services the child will need; (For children ages birth through 2 years, the IFSP is used.)

Individualized Family Service Plan (IFSP) - a written statement for an infant or toddler (ages birth through 2 years old) developed by a team of people who have worked with the child and the family; the IFSP must contain the child's level of development, strengths, and needs, major goals or outcomes expected, services needed, date of the next evaluation, and the starting date of the present IFSP

lead agency - the agency (office) within a state or territory in charge of overseeing and coordinating early childhood programs and services

Least Restrictive Environment (LRE) - an educational setting or program that provides a student with disabilities the chance to work and learn to the best of his or her ability; it also provides the student with as much contact as possible with children without disabilities, while meeting all of the child's learning needs and physical requirements

occupational therapy - a therapy or treatment provided by an occupational therapist that helps individual developmental or physical skills that will aid in daily living; it focuses on sensory integration; on coordination of movement; and on fine motor and self-help skills, such as dressing, eating with a fork and spoon, etc.

parent training and information programs - programs that provide information to parents of children with special needs about acquiring services, working with schools and educators to ensure the most effective educational placement for their child, understanding the methods of testing and evaluating a child with special needs, and making informed decisions about their child's special needs

physical therapy - treatment of (physical) disabilities given by a trained physical therapist (under doctor's orders) that includes the use of massage, exercise, etc. to help the person improve the use of bones, muscles, joints, and nerves

placement - the classroom, program, and/or therapy that is selected for a student with special needs

policy/policies - rules and regulations; as related to early intervention and special education programs, the rules that a state or local school system has for providing services for and educating its students with special needs

private therapist - any professional (therapist, tutor, psychologist, etc.) not connected with the public school system or with a public agency

program(s) - in special education, a service, placement, and/or therapy designed to help a child with special needs

psycho-social (development) - the psychological development of a person in relation to his or her social environment

psychologist - a specialist in the field of psychology, usually having a Master's degree or Ph.D. in psychology

public agency - an agency, office, or organization that is supported by public funds and serves the community at large

Public Law(P.L.)94-142 - a law passed in 1975 requiring that public schools provide a "free, appropriate public education" to school-aged children ages 3-21 (exact ages depend on your state's mandate), regardless of handicapping condition; (also called the Education for All Handicapped Children Act)

Public Law(P.L.)99-457 - an amendment to P.L.94-142 passed in 1986 which requires states and territories to provide a "free, appropriate public education" to all children ages 3-5 by the beginning of a state's 5th year of participating in the Part H Program and provides funds for states and territories to offer programs and services to infants and children (ages birth through 2 years) with disabilities

related services - transportation and developmental, corrective, and other support services that a child with disabilities requires in order to benefit from education; examples of related services include: speech pathology and audiology, psychological services, physical and occupational therapy, recreation, counseling services, interpreters for the hearing impaired, and medical services for diagnostic and evaluation purposes

services/service delivery - the services (therapies, instruction, treatment) given to a child with special needs

special education - see special education programs and services

special education coordinator - the person in charge of special education programs at the school, district, or state level

special education programs/services - programs, services, or specially designed instruction (offered at no cost to families) for children over 3 years old with special needs who are found eligible for such services; these include special learning methods or materials in the regular classroom, and special classes and programs if the learning or physical problems are serious

special needs - (as in "special needs" child) - a term to describe a child who has disabilities or is at risk for developing disabilities who requires special services or treatment in order to progress

speech/language therapy - a planned program to improve and correct speech and/or language or communication problems in people who are not thought to be able to improve without such help

INFORMATION ABOUT PUBLIC LAW 94-142

The Education for All Handicapped Children Act

Going to school and getting an education is every child's right. This is true for children with **disabilities** as well. They have the right to go to school and to learn academic and social skills in ways that meet their special needs.

To make sure that children with **disabilities** have these rights, Congress passed a law in 1975 known as **Public Law(P.L.)94-142**. This law requires that all states (and territories) provide a public school education to children, ages 3 to 21, (unless state law or practice does not provide for public school **services** for children 3-5 or 18-21), no matter how severe their **disability(s)** are. Under **P.L.94-142**, all children with **disabilities** have the right to learn to the best of their abilities.

There are several basic rights that this law promised to children, with **disabilities** (ages 3 to 21) and their parents:

- The right to a "**free, appropriate public education**" at public expense (in some cases, this may include placing a child in a private school);
- The right to an educational **placement** that is based on an **assessment** and **evaluation** of each child's own special needs;
- The right for children with **disabilities** to receive teaching or instruction that is designed to meet their needs; these needs are to be clearly written and included in an **Individualized Education Program (IEP)** for each child, with statements about what **services** the child will receive;
- The right to a full range of educational **services** that may include **related services** such as **counseling**, special transportation, **speech/language therapy**, or **occupational** or **physical therapy**;
- The right for parents (or guardians) to be included in making decisions about their child's educational needs and to approve the educational plans for their child; and
- The right for parents (or guardians) to **appeal** any decisions made about the **identification**, **evaluation**, and **placement** of the child through a **due process procedure**.

Finally, **P.L.94-142** requires that children with **disabilities** be educated in the **"Least Restrictive Environment" (LRE)**, that is, in the most normal school setting possible, with special help provided.

For more information about P.L.94-142, please contact:

NICHCY
P.O. Box 1492
Washington, D.C. 20013

INFORMATION ABOUT PUBLIC LAW 99-457

The Education of the Handicapped Act Amendments of 1986

In October, 1986, Congress passed a very important **special education** law called **Public Law(P.L.)99-457**. This law is an **amendment** to **P.L.94-142** and is an important step forward in educating your children with **disabilities**.

Under **P.L.99-457**, Congress has made funds available to help states and territories who want to continue receiving federal funds under the infant, toddler, and preschool programs to provide the following **services**:

- **Early Intervention Services** to infants and toddlers (ages birth through 2 years) with **disabilities** no later than the beginning of a state's 5th year of participation in the Part H Program. If a state chooses to, it can also serve infants and toddlers **at risk** of developing **disabilities**; and
- **Special education programs** and **related services** to preschoolers (ages 3 through 5 years) who have **disabilities** no later than school year 1991-92.

The term "handicapped infants and toddlers" in **P.L.99-457** refers to children (ages birth through 2 years) who need **early intervention services** in any of the following five areas:

- Physical,
- **Cognitive**,
- **Speech** and **language**,
- **Psycho-social**, and/or
- Self-help skills.

Early intervention services must be provided by people who are qualified to work with infants and toddlers who have **handicaps** or who are **at risk** for developing **disabilities**. Any **services** provided must be written into an **Individual Family Services Plan (IFSP)** that is reviewed every 6 months.

Public Law 99-457 also assures that all the rights and protections under **P.L.94-142** extend to all preschool children (ages 3-5 years) with **disabilities**. It strengthens and expands current **programs** for preschoolers with **disabilities** (ages 3-5 years) and increases the funding available for developing and improving such **programs**. **Public Law 99-457** is important because it recognizes that some infants and toddlers will need **early intervention** because they already have, or most likely will have, a delay that will have an impact on future learning.

For more information about P.L.99-457, please contact:

NICHCY
P.O. Box 1492
Washington, D.C. 20013

REFERENCES FOR FAMILIES

Books

Featherstone, H., *A Difference in the Family: Living with a Disabled Child*. 1981. New York: Penguin Books.

A book about the anger, fear, frustration, and joy a family experiences in caring for a child with handicaps, based on the author's own experiences with her severely handicapped son.

Fewell, R., & Vadasy, P., Eds., *Families of Handicapped Children: Needs and Supports Across the Life Span*. 1986. Austin, TX: Pro-Ed. (Available from Pro-Ed, 5341 Industrial Oaks Blvd., Austin, TX 78735.)

A book describing the many issues facing families of special needs children and the experiences of family members in their roles within the family "system." Provides information on support systems outside the family, including school-based, medical, and community services, and support from one's own religious community.

Goldfarb, L.A., Brotherson, M.J., Summers, J.A., & Turnbull, A., *Meeting the Challenge of Disability or Chronic Illness - A Family Guide*. 1986. Baltimore: Paul H. Brookes Publishing Co. (Available from Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624.)

A book covering the issues faced by families who must care for a family member with a disability or serious illness. Discusses in detail the common problems that these families face, suggests ways families can get needed support based on their strengths and needs, and offers advice on how each family can define and take steps to solve the unique problems it faces. Contains an extensive resource section, and practical exercises for defining problems, for assessing family needs, strengths, and weaknesses, and for solving problems.

Simons, Robin, *After the Tears: Parents Talk about Raising a Child with a Disability*. 1987. New York: Harcourt Brace Jovanovich, Publishers.

A book about parenting a child with a disability as told by parents of children with disabilities. Their stories provide insight into the complexity of emotions and events experienced in their efforts to recover a normal life. Dealing with feelings of isolation, relatives, siblings, the school system and the future are some of the issues addressed. A resource appendix is included.

Thompson, Charlotte E., *Raising a Handicapped Child: A Helpful Guide for Parents of the Physically Disabled*. 1986. New York: William Morrow and Co., Inc.

A practical guide for parents new to the issues of disabilities or chronic illness. Offers suggestions on how to make decisions under pressure, find helpful professionals, cope with the costs of raising a child with handicaps, handle progressive disease and death, and how to survive parenting a special needs child. Includes extensive references and resources sections.

Tingey-Michaelis, C., *Handicapped Infants and Children: A Handbook for Parents and Professionals*. 1983. Austin, TX: Pro-Ed. (Available from Pro-Ed, 5341 Industrial Oaks Blvd., Austin, TX 78735.)

A book about long-term, home care of children with handicaps. Contains practical information on meeting the needs of a child with handicaps with minimal disruption to the family.

Turnbull, Ann P. & Turnbull, H. Rutherford, *Families, Professional and Exceptionality: A Special Partnership*. 1986. Columbus, Ohio: Merrill Publishing.

A book that addresses the issues of the unique and interdependent roles that families and professionals assume in caring and advocating for individuals with disabilities.

Other Printed Materials

Parents Guide to the Development of Pre-School Handicapped Children: Resources and Services. October, 1984. No. 84-5. (Available form National Library Service for the Blind and Physically Handicapped, The Library of Congress, Washington, D. C. 20542.)

A listing of national organizations and producers and distributors of materials and services designed to assist parents in promoting their child's development in the early years.

Parent Helper - Handicapped Children Birth to Five. Maryland State Department of Education. 1982. (Order from Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402.)

Handbooks on Socialization, Communication, Cognition, and Motor Development.

Parent Resource Directory For Parents and Professionals Caring for Children with Chronic Illness or Disabilities. 2nd edition. January, 1988. (Available from the Association for the Care of Children's Health, 3615 Wisconsin Ave., N.W.. Washington, D.C. 20016. Phone (202) 244-1801 or 244-8922.)

A directory for parents and professionals to use to network and collaborate with others who care for or provide services to children having special health care needs. A resource for helping both parents and professionals develop partnerships at the state and local levels.

Selected Readings for Parents of Preschool Handicapped Children: A Bibliography. July, 1986. No. 86-1. (Available from National Library Service for the Blind and Physically Handicapped, The Library of Congress, Washington, D.C. 20542.)

A bibliography of a representative selection of books and periodicals in the area of preschool handicapped children, with emphasis on publications since 1979.

The Exceptional Parent. A magazine published eight time a year for parents, individuals, organizations, librarians, schools and agencies. (Available from The Exceptional Parent, 605 Commonwealth Ave., Boston, MA 02215. Phone: (617) 536-8961. Also available at some book stands.)

This document was developed by Interstate Research Associates, Inc., pursuant to Cooperative Agreement #G0087C3051 with the Office of Special Education Programs of the U.S. Department of Education. The contents of this document do not necessarily reflect the views or policies of the Department of Education, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government. This information is in the public domain unless otherwise indicated. Readers are encouraged to copy and share it, but please credit the National Information Center for Children and Youth with Handicaps.

This document was prepared for publication on the Macintosh®SE and LaserWriter®II NT through the generosity of Apple Computer®, Inc.

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PARENT'S "NEXT STEP" RECORD-KEEPING WORKSHEET

The sample record-keeping worksheet below can help you start a file of information about your child. As you contact different people and places, it's a good idea to keep records of people you've talked with and what was said. As time goes on, you will want to add other information to your file, such as:

- Letters and notes (from doctors, therapists, etc.);
- Medical records and reports;
- Results of tests and evaluations;
- Notes from meetings about your child;
- Therapist(s') reports;
- IFSP and IEP records;
- Your child's developmental history, including personal notes or diaries on your child's development;
- Records of shots and vaccinations; and
- Family medical histories.

Make sure you get copies of all written information about your child (records, reports, etc.). This will help you become an important coordinator of services and a better advocate for your child. Remember, as time goes on, you'll probably have more information to keep track of, so it's a good idea to keep it together in one place.

SAMPLE RECORD-KEEPING WORKSHEET

Problem/Topic: _____

Name of person or agency you talked to: _____
Name of your contact person
(may be same as above): _____

Date you called: _____ Phone # _____

Results of Discussion: _____
_____
_____
_____
_____

Action taken
(if any): _____
_____
_____
_____
_____

Person not helpful in this topic, but may be helpful regarding
(list topics/areas/issues): _____
_____
_____
_____
_____